



Yale School of Medicine

Department of Pediatrics

P.O. Box 208064

New Haven, CT 06520-8064

March 25, 2012

Support for Raised Bill No. 369 – An Act Concerning Authorization For The Use of Feeding Tubes and Antiepileptic Medications In School Settings

Dear Members of the Connecticut State Senate Public Health Committee:

As a full-time practicing pediatric neurologist and epilepsy specialist who has treated children with epilepsy for over 25 years, I am writing to register my support of Raised Bill No. 369 which would allow trained non-medical personnel in schools to administer FDA approved emergency antiepileptic medications (e.g. oral or rectal diazepam) to school children in the case of an unexpected prolonged seizure. On behalf of the roughly 5000 children and adolescents in Connecticut living with Epilepsy, I welcome and support the initiatives the Epilepsy Foundation of Connecticut to assure that children with epilepsy have appropriate and timely access to safe and effective medication. Stopping seizures promptly allows children to more fully participate in their educational experiences.

The use of FDA approved antiepileptic medications in schools has become a very important topic to many families of children with epilepsy. All child neurologists are aware of multiple situations in which children with epilepsy who are prescribed antiepileptic medications have incurred unnecessary medical risks because educators and child care service providers refuse to make the medications readily available onsite. Children have been excluded from programs because of the false belief that certain treatments must be administered or applied by a medical professional, or that extensive monitoring is required. In addition to the medical risks and potential injury, when calling 911 or other emergency responders instead of administering emergency antiepileptic medications on-site in a timely manner, families often incur significant expenses as well as unnecessary ambulance rides and emergency room visits.

Raised Bill No. 369 allows trained school personnel to implement the treatment plan given to them by the parents and the child's physician. The actual judgment and decision to give emergency antiepileptic medication is the same judgment and decision the parents would make at home: *any caregiver who would consider calling "911" should have already considered giving the prescribed emergency antiepileptic medication first.* Just as Boy Scout leaders are trained in first aid and by-stander CPR (cardio-pulmonary resuscitation) by the American Red Cross, trained school personnel should be in the position to implement the emergency antiepileptic medication treatment plan (which is much easier to learn than by-stander CPR). Raised Bill No. 369 allows trained school personnel to implement "first aid" and help a child in need. The benefits of giving these safe and effective medications as early as possible are enormous!

Diazepam is the most commonly used emergency antiepileptic medication. Diazepam was developed by original research in the late 1950s and was first marketed as Valium® in 1963. Intravenous diazepam has been used since the 1960s for controlling prolonged seizures (status epilepticus). It is also available in an oral form as well as a rectal gel, which was FDA approved in 1997.

Rectal diazepam is easy to give. The rectal drug-delivery system (e.g. Diastat®) offers an easy, safe, and bioavailable method—the absorption through the mucous membranes of the rectum is rapid and consistent. In adolescents, it may be preferable to give oral diazepam, but the planned route of administration could be easily spelled out in the individual child's existing Individual Health Plan (IHP), Individual Education Program (IEP) or Section 504 plan.

The Epilepsy Foundation of Connecticut is well aware of concerns raised in opposition to our view. We feel that these concerns regarding evaluation and assessment of the seizure, wrong dosing and dangers of the drug and its recommended administration are unfounded. Studies in both children and adults with epilepsy show rectal diazepam to be safe and effective in stopping breakthrough seizures. No significant medication-related adverse events are seen with repeated administration of this antiepileptic medication. Rectal diazepam significantly reduces the likelihood of seizure recurrence during an episode of acute repetitive seizures, with minimal safety concerns.

Mitchell WG, Conry JA, Crumrine PK, et al. An open-label study of repeated use of diazepam rectal gel (Diasat) for episodes of acute breakthrough seizures and clusters: safety, efficacy, and tolerance. North American Diasat Group. *Epilepsia* 1999;40:1610-7.

Cereghino JJ, Cloyd JC, Kuzniecky RI. Rectal diazepam gel for treatment of acute repetitive seizures in adults. *Arch Neurol* 2002;59:1915-20.

Federal and state laws guarantee every child/student the right to participate in free, appropriate public education in the least restrictive setting. Schools are also required to provide many health-related services, including administering medicine, if needed, to students with disabilities, as either a reasonable accommodation or a related service. The purpose of these laws is to ensure that children with chronic health conditions—like epilepsy—can be educated in the least restrictive environment and participate in extracurricular and recreational activities with their peers. Because medicines, including rectally or orally administered diazepam, can be administered by nonmedical personnel who have received proper instruction, lack of access to a doctor or full-time nurse is not an acceptable reason to refuse to administer the medication on-site or to deny a child or student access to certain school activities. The Epilepsy Foundation wholly supports these principles as being in the best interest of the child.

The Epilepsy Foundation of Connecticut urges providers of childcare and educational services to work with the child, his or her parents and the child's treating physician to learn how and when to administer the appropriate treatment. Schools and service providers should, along with the child's parents and as appropriate, the treating physician, develop a plan for ensuring that adequate measures are taken to administer the treatment and that the appropriate staff is properly trained to do so. Such a plan may legally be a part of an Individual Health Plan (IHP), an Individual Education Program (IEP), a Section 504 plan or simply a plan required to ensure compliance with the Americans with Disabilities Act of 1990 (ADA); the critical point is that a mutually satisfactory approach that allows the child or student complete access to educational opportunities can and should be developed to cover the potential need for administration of emergency antiepileptic medications.

The basis for an Individual Health Plan (IHP) is to benefit schools by:

- Protecting individual and district liability of school boards and administrators
- Documenting compliance with federal and state laws and regulations
- Providing data about individual needs for staffing, professional development, policies, and cost-effective use of school and community resources

The basis for an Individual Health Plan (IHP) is to benefit children and families by:

- Avoiding unnecessary risk, restriction, stigma, school absence, and additional illness
- Coordinating academic goals with physical, social, and medical needs
- Emphasizing academic and medical continuity
- Increasing sensitization by both school staff and peers about the medical needs of others
- Providing medically timely and convenient access to medication at all times, and
- Outlining individualized crisis and emergency management needs

An IHP provides opportunities for collaborative planning and problem-solving between school staff and parents. Every student with a health impairment or physical disability needs documentation of their needs and the services to be provided through an IHP. The IHP clarifies the provision of medication, monitoring of health status, and other aspects of health management.

What are the consequences of not having an Individual Health Plan (IHP) that includes the use of FDA approved emergency antiepileptic medications?

- Students can't reliably receive medication as needed
- School staff do not understand the precautions necessary to avoid hazardous situations
- School staff can't assist students to overcome obstacles to participation and achievement

Emergency antiepileptic medication (such as oral or rectal diazepam) can be safely used for management of acute repetitive seizures in both children and adults. Diazepam is approved by the FDA for the intermittent management of breakthrough seizures in patients with epilepsy on stable regimens of anti-epilepsy drugs. Emergency antiepileptic medication (such as oral or rectal diazepam) helps to control bouts of increased seizure activity.

Because medicines, including orally or rectally administered diazepam, can be administered by nonmedical personnel who have received proper instruction, lack of access to a doctor or full-time nurse is not an acceptable reason to delay urgent administration of the medication on-site, or to deny a child or student access to certain school programs. The Epilepsy Foundation of Connecticut wholly supports these principles as being in the best interest of the child. Our position—that trained, non-medical personnel can safely administer emergency antiepileptic medications—is endorsed by our Professional Advisory Board comprised of clinicians, scientists and other professionals with expertise and interest in seizure disorders. Thank you for your consideration and support for Raised Bill No. 369 to allow trained, non-medical personnel in our schools to help protect children with epilepsy.

If you have any questions please feel free to contact me at william.graf@yale.edu.

Submitted respectfully to the Connecticut State Senate Public Health Committee,

William Graf, MD (electronic signature in this pdf document)

William D. Graf, MD, FAAP, FAAN
Professor of Pediatrics, Departments of Pediatrics and Neurology
Yale University, PO Box 208064
333 Cedar Street
New Haven, CT 06520-8064
william.graf@yale.edu